



## NEWBORN SCREENING FACT SHEET

### POSITIVE HEMOGLOBINOPATHY SCREENING TEST RESULT FOR AN ABNORMAL HEMOGLOBIN

#### WHAT DOES A POSITIVE SCREENING TEST RESULT FOR AN ABNORMAL HEMOGLOBIN MEAN?

Hemoglobin is the chemical that carries oxygen in the red blood cell. Some times changes within this chemical occur. Sometimes these changes can cause problems, while other changes are harmless. A screening test result that is positive for the presence of an abnormal hemoglobin type means that your baby's blood was found to have an abnormality. It does not tell whether or not this abnormality is harmful to your baby.

#### WHY IS THIS SCREENING TEST RESULT IMPORTANT TO YOU, THE PARENTS?

Many people are unaware that they have abnormal hemoglobin, and are unaware that they could pass this trait to their children. It is important to confirm this finding and to get counseling to better understand the meaning of this result for your child, and to better understand what this means for you, if you decide to have more children.

#### WHAT SHOULD A PARENT DO WITH THIS SCREENING TEST RESULT?

Because the screening test cannot tell if your baby has a serious hemoglobin disorder or not, your baby needs to be tested again to determine the nature of the abnormality. Once this information is

known, counseling is available to help you understand the risks that your baby might face because of this problem and the chances for you, of having other babies who might have this problem as well.

Once the abnormality is confirmed, you should make sure that it is clearly documented in your baby's medical record to eliminate the need to have any more tests done.

When your baby is older, you should be sure that your child understands that they may also have a baby with abnormal hemoglobin.

#### WHO CAN I CONTACT FOR MORE INFORMATION?

You can obtain more information from your baby's doctor, about abnormal hemoglobins and other specialists available. Genetic counseling to discuss testing options and family risks for hemoglobin problems is available through clinics at various sites around the state by genetics specialists from UNMC. To schedule an appointment, you can call (402) 559-6800 or (800) 656-3937. Specialists in Hematology are available at: James Harper, MD- UNMC (402) 559-7257; David Gnarra, MD-Children's (402) 955-3950, Dr. Howard Koch-Alliance (308) 762-2125.